The power of the personal story

For me, the articles sent in by our readers are the highlight of each issue of The Beacon. However, I have to say that this time, they have moved me to the point of tears. The pieces are so REAL, so full of emotion, so candid and so compelling.

Why this time more than others? I think it’s because these women are prepared to speak out on the effect of their breast cancer treatment and diagnosis on a topic that’s been shoved under the carpet for so long – their sexuality. It’s sensitive and it’s personal – and it’s also having a major impact on women.

You can feel the raw pain, frustrations and sense of loss as they struggle to recapture longed-for and sometimes lost pleasures enjoyed before their diagnosis. So many are worried about the impact of sexuality issues on their partners.

For BCNA, confronting the issue and talking openly about it is the first step. Advocating for our members is our key work and we intend to undertake research to learn more about the extent of the problem across Australia. We need to explore strategies to help women feel empowered, rather than defeated. We need to encourage doctors to proactively raise the topic, and for them to be able to refer patients on to someone who can offer practical help and advice. We need increased quality information and resources. We need to hear from you, anonymously if you prefer, if you have something to add to our considerations.

Later this month, we are excited to be launching the second edition of the My Journey Kit, our resource for Australians newly diagnosed with breast cancer. When we sought feedback from women who’d received and used the Kit, a common concern was that the first edition barely mentioned sexuality and intimacy issues. This has now been rectified with a new chapter of the Kit’s Information Guide dedicated to this.

When I realised this is our 50th issue of The Beacon, I revisited my editorial in the first newsletter in the summer of 1997/98 where I wrote: ‘This newsletter will provide a forum for the issues around breast cancer to be raised and shared’. Over the years, we have raised many concerns. They’re not necessarily issues of great science, discovery or clinical understanding, but they are what was intended: real issues, faced by real women and men. To share our worries and to read how others face challenges, to be inspired by the courage and tenacity of women, helps us all to deal with what we face along our own breast cancer journeys.

Crucially, if we don’t raise our issues, they simply won’t be addressed by those with the power and influence to bring about improvements. And we all know full well about the power of the personal story, don’t we?

Lyn Swinburne
Chief Executive Officer

The second edition of the My Journey Kit is now available for Australians who have been newly diagnosed with breast cancer.

Throughout this issue of The Beacon we share some of the beautiful photos that feature in the new My Journey Kit. These photos are indicated with a MJK caption.
‘One of the big differences between women and men is that generally women need to feel good in order to feel sexy, whereas men often seek sex in order to feel good.’ – Sandra Pertot

Dr Sandra Pertot has worked as a clinical psychologist and sex therapist for more than 30 years. She has written three books and many articles on sexuality. The Beacon spoke to Dr Pertot about sexuality issues for women with breast cancer.

Are changes to sexuality a common experience after a breast cancer diagnosis?

A lot of women find their sexuality is changed. It can be affected by their emotional reaction to their diagnosis, the effects of the disease, and the side effects of treatments.

Every woman will have her own reaction. You might be desperate to maintain your sexual identity and want sex a lot. You might seek sex for comfort and reassurance, but find your old physical responses are not there. Or you might lose interest in sex altogether.

It is important to accept that the feelings and responses you experience are normal and are appropriate for you.

How can I manage my relationship with my partner?

Sometimes there can be long periods without sex because of stress caused by breast cancer. This can affect relationships. When I see couples in this situation I acknowledge how sad it is for them both, as it is not just the partner who is missing out on sex; the woman is missing out too.

The loss of your sex life, or the sex life you are used to, is part of the grief process. It can help to tell your partner that you know it is frustrating for him as it is for you too. Many partners don’t realise you may be sad about losing your sex drive.

The loss of sex drive is often a challenge for women who feel sorry for their partners. While you can understand that your partner is unhappy about not having sex, sex can only be meaningful for you if there is something in it for you. It’s not a good idea to allow sex to happen just to satisfy your partner, especially if you are then going to feel used and not cared about.

However, if you think about what makes sex okay for you, you may find reasons to have sex even if they are very different to what you wanted in the past.

Try talking with your partner about how you both are feeling. If you can have an honest discussion, it will make things easier. Find gentle ways to tell him what is happening to you and ask him how he is feeling. Tell him what you want – ‘I really like it when you cuddle me because it makes me feel safe and reassured’.

Some women avoid intimacy in case it leads to sex. Let your partner know if what you need is affection but not sex. You can say ‘I really feel good when we cuddle, but I don’t feel I can have sex at the moment’.

If you do want to have sex, try to be clear about what you do and don’t want. You may not want your breasts touched, or you may not be able to reach orgasm. You may need to change your usual positions. You and your partner may have to negotiate a new way of having sex.

What about single women who want to be sexually active?

For single women, it is about confidence and knowing how to talk about what has happened to you. When to have this conversation can be tricky. You may like to have it early in the relationship as part of the ‘getting to know you’ process. The risk is that sharing the information might end the relationship, but it is better to know that early than to get involved and have the conversation when you are ready to move to a more intimate stage of the relationship.

Will things get better?

Whether you are single or partnered, it is important to allow yourself time to re-establish your sex life. Adjusting to your changed sexuality is like any grief. Some women can move on within a few weeks, others are still grieving 12 months later. There is no correct timeline – take your own time and trust your own instincts and emotions.
Sexual confidence and barriers to sexuality

‘At first, because of the big change in my body, I felt very unsexy. I had only one breast and had put on weight. It certainly does something to your self-esteem.’ – Louise

Cancer treatments can affect sexuality in many ways.

There are physical effects such as fatigue, breast tenderness, pain and loss of sensation. Some chemotherapy and hormonal therapy treatments can result in vaginal dryness and/or loss of libido. We can also feel less attractive because of the changes treatment brings to our bodies – weight gain or loss, hair loss, loss of a breast, and scars. These can be difficult for us to accept.

You may find that you have lost confidence in yourself, or that you are suffering emotional trauma as a result of your diagnosis.

‘My partner would stay up late and then come to bed after I was asleep. He wouldn’t talk about it, but I think I was unsure how to approach me sexually.’ – Jan

Sometimes partners have trouble accepting the changes to you, and your body, too. It may be difficult for them to express how they are feeling, and to understand how you are feeling. Sometimes partners stop making sexual requests, as they don’t want to pressure you, are frightened of hurting you, or simply don’t know how to address the situation.

‘Stay tactile – kisses, massages and hugs (it doesn’t have to be sexual) – so that you can express your love for each other.’ – Maxine

Intimacy and sexuality is not just about sex. There may be times when being close to your partner is enough.

When you do feel ready for sex, you may find that your favourite love making positions have become less comfortable. You may need to keep an open mind about new ways to feel sexual pleasure. You may have to experiment with new positions, or use pillows and cushions to support you and take pressure off sore spots. Oral sex may allow tender parts of your body to heal while providing enough gratification to keep both you and your partner content.

‘I tried a vibrator to reconnect with my sexuality without the pressure of failed intercourse or affecting my partner.’ – Sharon

Many women find adult products can enhance their sex life, either with their partner or on their own. Adult stores have an extensive range of erotic books and DVDs, and products such as clitoral and vaginal vibrators and dildos. If you are not comfortable visiting your local adult store, you can shop online through an internet site.

Experimenting on your own may help you to discover what the ‘new you’ does or doesn’t enjoy before resuming your physical relationship with your partner. It may involve letting go of feelings of guilt and inhibition, but you will not harm yourself and no one will know if you do it or don’t!

There are also people you can speak to about difficulties you may have adjusting to the changes to your body. Your Breast Care Nurse or GP may be able to help, or your GP can refer you to a psychologist, sex therapist or counsellor. It may take courage for you to take proactive steps, but these practitioners are experienced in these issues and they will probably remind you that these challenges are often experienced by people in similar situations to yours.

‘I am a member of an online forum that enables me to read of other women’s experiences with their sexuality and their limitations in that area since having breast cancer. It’s helped me to see that it’s not my fault that I feel the way I do, and my reservations about sex and intimacy are experienced by many women who have had breast cancer.’ – Kerri-Ann

Online forums and breast cancer support groups are often helpful too – many women are happy to talk about their experiences and share advice about things that have worked for them.
An end to spontaneity

The thought of getting my life back was a big incentive during my bumpy cancer journey. I was 43 years old, a single mum of two girls aged 9 and 12 and, miracle of miracles, I met a wonderful man during this time – talk about someone seeing you warts and all!

The relationship continued to flourish despite my diagnosis and treatment, and after a while the three of us moved into his home. We were so happy; he had met the woman of his dreams and I had met my prince. To say life was good was an understatement, I was euphoric!

My euphoria was shattered a year later when, without warning, sex suddenly became not only unbearably painful, but virtually impossible. We invested in lubricants but to no avail. The next step was medical help where surgery was suggested. However, as I had already had two lumpectomies, a mastectomy, and chemotherapy (which had thrown me into early menopause) I was reluctant to have more surgery and besides, there was no guarantee of a return to our healthy sex life, so I decided against it.

Spontaneity became a thing of the past; any attempt at sex was a major planned event. I found that I was just not interested in any lovemaking activities and try as I might to please my partner, it just was not the same.

In spite of physical, mental and emotional efforts, the relationship deteriorated and eventually the strain proved too much and my daughters and I moved out.

Although the outcome is different to the original plan, my ‘prince’ and I still see each other but there is a void in our relationship which cannot be crossed. Our pleasure in each other’s company and mutual respect for each other as human beings is what drives us in our now platonic relationship.

Certainly, the breast cancer experience has impacted on my sexual life but hey, I am here to tell the tale and have been given the gift of seeing my girls evolve into young adults and for that I am truly thankful and I am happy now to just keep on keeping on!

Toni

Vaginal dryness: a common problem

‘Chemotherapy sent me into early menopause and I suffer a lot from vaginal dryness and seem to have lost my interest in sex.’ – Sharyn

Vaginal dryness can be a distressing side effect of some breast cancer treatments, and one that is not often talked about.

Vaginal dryness is associated with menopause, both natural and early menopause brought on by cancer treatments. Oestrogen levels drop after menopause, causing the vaginal walls to become thinner and less flexible, and to produce less lubricating fluid.

Symptoms of vaginal dryness can include burning and itching. Sex may become painful and may result in vaginal bleeding. Some women become more prone to yeast infections such as candida.

At the same time, the pelvic muscles can weaken and sometimes incontinence occurs if these muscles become too weak to stop urine leaking through from the bladder. Sometimes this muscle weakness also allows prolapse to occur.

Unfortunately, unlike other menopausal symptoms, vaginal dryness does not tend to improve over time if left. There are a number of products you can try if you experience vaginal dryness.

Many women use non-hormonal vaginal moisturisers, such as Replens, which help the vaginal walls to retain moisture and elasticity. They are usually applied two to three times a week and are available from pharmacies. Research by BreastCancer.org in the US found that women’s vaginal symptoms and sexual function improved after using Replens, although often it took a few months to be effective.

A water-based vaginal lubricant, such as Syk or Astroglide, can be used during intercourse to make sex more comfortable. Studies have shown that olive oil is also a safe and effective lubricant. Lubricants can be used in conjunction with vaginal moisturisers. They are available from supermarkets and pharmacies.

If sex is still painful, you might like to try a thick barrier cream such as Bepanthen.

Vaginal oestrogen creams can also relieve dryness but doctors are cautious about prescribing them for women who have had breast cancer, particularly oestrogen-positive breast cancer. These creams contain low doses of oestrogen, which may be absorbed into the body. You may like to discuss with your doctor whether an oestrogen cream is suitable for you. You will need a prescription to purchase one.

Other ways of managing vaginal dryness include not using products that could irritate or dry the vaginal area, such as soaps, perfumes and baby oil.

Try sorbolene for washing. Cotton underwear is much gentler than nylon.

Pelvic floor exercises can also help; building vaginal muscle tone, increasing lubrication and improving continence.

If you are concerned about vaginal dryness, don’t be afraid to talk to your doctor about how best to manage it. Although your doctor may not raise it with you, it is a common problem among post-menopausal women.
Tattooed for life

For 20 years I worked in a cytology lab diagnosing cancer. During that time my sister was diagnosed with breast cancer while two aunts died of the disease. With such a strong family history and intimate knowledge of oncology, I was closely monitored, and was fortunate to be diagnosed at a very early stage. I immediately opted for a bilateral mastectomy.

‘Why not wait a while and see what happens?’ my husband asked. For me, however, waiting was not an option and this decision had to be mine.

Soon after the operation, I realised how important my breasts had been to him. He rejected me in more ways than one. I tried to maintain a positive outward appearance but within two years I was divorced. Around this time my sister died, my son was diagnosed with schizophrenia and subsequently died, and I was made redundant from my job. Not surprisingly, I fell in a hole.

When I picked myself up, I realised I was free to do the things I had always wanted to. I sailed on a tall ship, I farmed goats, I enrolled in university, and I travelled, but I never expected to have another sexual relationship. I had no regrets about my radical surgery, but I hated the ugly scars which it left me with. How could I ever show my scarred chest to a man?

One day, I noticed a tattoo on a girl’s shoulder - a delicate grey etching of a briar rose. I admired it and asked her where she had had it done.

It took all my courage to walk into the tattoo parlour but the artist put me at ease. We talked about the design and after having a tiny rose tattooed on my hip, I decided to go ahead and have a floral design tattooed on my chest. When the work was finished, I was delighted.

A couple of years later I met Peter on a cruise ship – a relationship straight out of The Love Boat. I felt confident and was not ashamed of my appearance. Peter and I had two wonderful years together which only ended when he died tragically in a road accident. Two years ago I moved to Tasmania where I devote my time to writing and have had four books published.

Today, I do not have a partner, nor am I seeking one, but my tattooed chest has given me the self-confidence to welcome another relationship should it ever sail over the horizon.

A whole person

When I was diagnosed with breast cancer it was thought that I could avoid a mastectomy. I was enormously relieved. Appearance and sexuality suddenly became an overwhelming concern for me. However, it soon became obvious that a mastectomy would be necessary to provide the best possible outcome for survival.

Contemplating losing my breast was devastating as I felt that my appearance and sexuality would be changed forever and that I would never be a ‘whole’ person again. Prior to and after the mastectomy, I sought solace in comfort food, which resulted in kilos accumulating at an alarming rate. After all, I thought, what did it matter if I became overweight?

My husband had difficulty in supporting me emotionally, which I believe is not unusual, although he was as supportive as he knew how and was totally accepting of the fact that I had lost my breast, never once showing signs of rejection. It was I who had the sexuality and image problems which in hindsight impacted on a relationship that was already under stress.

After several months of emotional self-destruction, I knew that remedial action had to come from within, and that it was incumbent on me to turn the situation around and get my life back into perspective.

I decided to enrol in an educational course of interest at the local community college and embarked on a weight loss program including a daily walking regime. My efforts produced truly remarkable results! Achieving goals replaced my feelings of inadequacy and engendered much needed confidence and self-esteem which helped me to accept myself as a ‘whole’ person again, dispelling fears and phobias in relation to appearance and sexuality.

I now feel totally comfortable with my image and sexuality and plan to continue to achieve goals. I have adopted the attitude that I am indeed a whole person and that losing a breast is a small price to pay for survival. There are options for reconstruction in the future, but I don’t feel the need to pursue those options at present, if ever.
Battle scars

I was shocked when I looked down at my chest a couple of days after my mastectomy. Nobody had told me that it would not be flat as I expected; it was concave. I wasn’t in a relationship and all I could think was that if a man left me when I was whole, what chance did I have of anyone else wanting me now I was a freak?

Three years after the mastectomy I had reconstructive surgery. Even though I felt more balanced and much more comfortable than when I’d worn my prosthesis, it still took two more years of soul-searching to feel brave enough to contemplate the possibility of another sexual relationship. By that time I had qualified as a counsellor and had learned that although I had both breasts when my husband left, I hadn’t been ‘whole’ at all.

Eventually I met someone who wasn’t fazed by my ‘mutilation’. There’s no disguising the fact that my new breast is sewn on, that I have an abdominal scar from one hip to the other and I no longer have a navel. I was nervous when it came to the crunch but this wonderful man loved me, not what I looked like. He kissed my scars and said that he loved all of me.

This relationship was infinitely more intimate than my marriage had ever been because I now knew who I was. If a man rejects me today I know I will still be okay because I love me.

Even with a loving partner it can be hard to believe that you are still desirable. My advice to any woman whose body image is shattered after a mastectomy is to seek counselling or whatever it takes to believe that you are not your battle scars.

Jane

What’s in a pathology report?

Many women have told us they know little about what is in their pathology report or how it is used.

Your pathology report is critical to your treatment. It provides information about your cancer, including the size and stage of the tumour, and whether hormone receptors are present. The information is gathered from tests on tissue collected during a biopsy or your surgery.

Your oncologist or treatment team uses your pathology report to help identify the best treatment options for you.

We know pathology reports can be confusing, and that sometimes doctors don’t discuss them with women. You may not have ever seen your pathology report or had a chance to ask questions about it.

In consultation with the Royal College of Pathologists of Australasia, BCNA has produced a pathology fact sheet for women with breast cancer. It provides information about what is included in a pathology report, what the terminology means, and how you can obtain a copy of your report, even years after your treatment has finished.

The fact sheet is free of charge and can be downloaded online at www.bcna.org.au or phone us on 1800 500 258 (freecall) and we will send a copy to you.
More than my scars

A year or two before my actual diagnosis of breast cancer I had a lump biopsied. While waiting for the results I had a discussion with my then husband about breast cancer and mastectomies. I said that if cancer was found I would have the breast removed. He replied that I would have to have a reconstruction. ‘Couldn’t you love me with only one breast?’ I asked. I received no reply. Warning bells went off in my head.

After being diagnosed, while recovering from my mastectomy I needed help to wash and dry myself, but my husband wouldn’t help as he couldn’t look at my wound. He didn’t ask questions of any of the specialists and avoided talking about breast cancer. I felt like I was less of a woman without the breast. I became very self-conscious and withdrew from him completely. I couldn’t stand to be touched anymore. We have since separated.

My young son was curious and wanted to see the scar. He wasn’t horrified at all. I have a male friend who is not turned off by the scar and makes me feel all ‘woman’, but I am not confident in meeting other men and forming a relationship as I am not sure how they would react to seeing only one breast.

Some men joke about scars on their own bodies and act like they are trophies, but they treat a mastectomy scar differently. The loss of a limb doesn’t make you less of a person so it frustrates me that the loss of a breast can cause so many problems. At times I am very lonely and would like to have someone in my life, but I am not going to have a reconstruction just to please a man. I am quite comfortable with myself now and am considering having the remaining breast removed. I have joked about going from an A cup to whatever size I would like with prostheses. What the future holds I don’t know but at this point in time I think I will be single for quite a while yet.

Mary

BCNA’s Sexuality and Breast Cancer Research Project

‘My breasts are an important part of my sexuality, so the loss of sensation in the reconstructed breast was initially quite a challenge to accept.’ – Sasha

Sexuality is a topic not often discussed, but many women find there are changes in their sexuality and sex life after a diagnosis of breast cancer.

We recently invited members of our Review & Survey Group to take part in an online survey to find out more about this issue.

We received 243 responses from women, some single and some in relationships.

Overwhelmingly, 91% of women told us that their breast cancer diagnosis and treatment did impact on their sexuality.

We asked women to tell us about the kinds of physical and emotional challenges that they faced. The most common physical issues experienced by women were pain in the upper body or arm, and vaginal dryness, while the most common emotional challenges were a lack of interest in sex and not feeling attractive. More than 50% of women told us they had not discussed with anyone the challenges they were experiencing with their sexuality or sex life. The women who did seek support were more likely to speak to someone close to them, such as their partner or a friend. Single women raised many concerns about starting new relationships. Only 50% of single women told us they had started a new relationship after breast cancer treatment.

‘For a while I felt damaged in a very deep-seated way and completely convinced that no man would ever look at me again. One did though, and still does.’ – Marianna

Advice from women to others included being open with your partner, and using lubricants or sex aids to help you reconnect with your sexuality.

To read the report about sexuality after breast cancer, visit our website at www.bcna.org.au.
I am 58 years old and I was diagnosed with breast cancer six years ago.

I had a mastectomy and underwent six months of chemotherapy.

After my treatment I developed a bowel prolapse due to the strain and pressure of constipation during chemo. I put up with it for two years but then was advised by my local doctor to see a specialist.

Four years ago after a visit to a gynaecologist it was recommended that I have a bowel prolapse operation. It was suggested that they use a mesh-like substance instead of the older method of stitches as it was proven to be more successful. I was not told of any problems or side effects or long-term issues.

Within the first two years of the procedure I went back into hospital twice to have the mesh trimmed as it was cutting into my vaginal walls when I sat down, causing discomfort and sometimes bleeding.

My major problem is that I cannot have sexual intercourse as the mesh has no stretching capacity and the sharp edges of the mesh push into my partner’s penis on entry making the whole process impossible and painful.

I was at the stage where I needed to know the true story of the mesh used for this operation. I wanted to know how many women have had the same experience as me!

Is it just an isolated case or are other women embarrassed to discuss their personal and intimate details?

I am angry that I and my partner of 17 years, who has been through the highs and lows of this cancer journey with me, should have been robbed of our sexual life and intimacy in our past few years together.

We have a great relationship and I am blessed to have his love and support!

It is hard enough having to cope with your loss of body image due to a mastectomy and the effects of chemotherapy, only to recover and find you have other problems due to side effects of treatments.

When I had this operation I was never told that it could be the end of my sexuality.

To anyone who has a similar problem and is still sexually active, please question your doctor if you are offered this procedure – it fixes one problem but creates another!

Barbara

An unexpected side effect

For my lover

After the chemotherapy and the hormone therapy, they told us to expect it – this loss of libido.
But I didn’t understand what it meant, until now.
It’s desire that has gone and it hurts so much that feeling sexy, getting hot and excited, are just a memory (well, feeling hot is not, but that’s another story)
Where is that woman who reached for you in the night, who whispered stories that you love to hear?
Those wet, exciting nights (and days) of yesteryear are gone.
I feel so sad.
I love you, oh I love you
But I just don’t turn on like I used to.
Sex just isn’t sexy any more.
But it doesn’t feel right to be letting my thoughts wander while we make love. Which we do.
So starting from now I’m starting again to delve down deep to try to find the woman inside.
Who wants you, like you want me.
Like we used to be.

Sarah
From the moment my GP felt a lump in my left breast, I began a rapid journey from being a passionate, sexually vibrant woman in her prime, to being an asexual, and at times, invisible, older breast cancer patient. My breast became of great interest to a number of men, and as I stripped and bared all to them, with every examination, every test, and every stranger who prodded and poked at this most beautiful, intrinsically feminine part of me, the essence of my sexual self seemed to evaporate.

The surgery left my breast changed, and the chemotherapy made me sick. I was catapulted into menopause; a curiously asexual arid state in mind, body and spirit. I stood in front of the mirror at the end of all the treatment and thought; ‘I don’t know who I am anymore’. I despaired of ever feeling alive again, and yet I rejoiced at being given the chance of life!

I was nine months into a new relationship with a delightful man, who one month before my diagnosis had a serious traffic accident. I felt we had enough to deal with in our lives, and then came the breast cancer. We were newly in love and passionately enjoying our sexual relationship – when BAM – it was all ripped away from us.

We both boarded the rollercoaster of surgery; I went on to chemo and radiotherapy, and he began physiotherapy and rehabilitation. The loss of my sex drive became something I needed to mourn – along with all the other losses. We still had sex together, but it became so inhibited – it had to be planned, and done carefully and gently, and I invariably felt great sadness as the changes emphasised the loss. I looked at photos of myself prior to the cancer, and mourned the loss of the woman – the essence of who I had been. How do you grieve for a wet vagina, and the rush of exhilarating sex? And then I became aware of how invisible I had become. I used to walk down the street and men would look at me – and I took it for granted! Now they didn’t seem to even realise I was there. And saddest of all – I couldn’t seem to feel passionate. In fact, I couldn’t even feel like I was in my body – it was as though some alien form had become my self. Sex became mechanical and my body became mechanical. Full of aches and pains, and ravaged by the life-saving treatment. One loving friend said to me, ‘You’ve lost your sparkle!’ How do you grieve for lost sparkle?

I called in to see my gorgeous man one afternoon last week – it is 15 months since I was diagnosed with breast cancer, and 16 months since he was hit by a car while crossing the road. We hugged hello, and before I knew it, we were in bed – laughing and enjoying the passionate moments (carefully and with the odd groan when moving injured body parts!). I almost cry with joy when I think of it. I’m not sure how, but healing has occurred and I am in awe of its power. I know now that it is possible to come back to some sense of the sexual self. It is possible to be fully alive and passionate about sharing my body again. And in many ways, each time is more special than the last, as I thank the universe that I am alive and able to experience the exhilaration of physical love.

And I am grateful for having a partner who was honest about his grief at the physical losses, but who was wise enough to know that time would pass, and healing would occur. His patience, and capacity to adapt to our changed physical conditions, made my journey gentler. Patience, honesty, faith in each other’s journey, and the willingness to love unconditionally were keys for me in my intimate relationship, and in my understanding of myself. I feel like a teenager again when I think of sex. Of course, in reality, it’s all rather slow and painful, but hey … it’s good to be alive!

Heather

Patience, honesty, faith
Finding my libido

In July 2009 I had a mastectomy to remove my 'ticking time bomb'. I was the first person I knew to get any type of cancer or life threatening illness. It was all new to me.

I never worried about my attractiveness to my husband. It just wasn’t an issue for him. Absolutely a ‘boob’ man, he was much more an ‘Erin’ man. We had sex a lot in the first month or two. It still felt good and the closeness was important. It tapered off a bit through chemo – I was very tired and a bit queasy although I was never sick. I still enjoyed sex though.

By the end of the year (coinciding with the end of my treatment) things had really changed for me. Sex was painful (even when using a lubricant, which we’d never had to do before). It felt like someone had put sand in my vagina. I used to cry afterwards – not because of the pain, but because I was grieving over my lost sexuality. Once I started on Tamoxifen my libido disappeared. It was absolutely dead; nothing could revive it. I love my husband and know that sex is important for a relationship so we still did have sex, but it really meant nothing to me. That made me sad.

After about six months I started seeing a naturopath and this helped a lot with all the side effects. One day I mentioned the libido issue and she said ‘Oh, I can put some ‘sex’ herbs in.’ The herbs she included worked, not only on the libido, but also on the vaginal dryness. I am enjoying sex again, and my husband is more comfortable initiating it because he knows that.

I have always been a very sexual person. It was hard for me to see myself otherwise. Who was I if not this highly sexed woman I’d always been? It took me some time to work through this, but I realised that there had always been more to me than that, and without it I was still a good person, with a lot to offer. I’m glad to have my interest in sex back again, but I’m also very grateful for the opportunity to find and embrace the other parts of me which were neglected, and undervalued in the past. For the first time in a really long while I don’t worry about my body shape either. I worry about feeling well and being healthy – not about some idealistic goal to have the ‘perfect body’. I guess I’ve made peace with myself and it feels good.

I never had any problems talking about sex, but I initially found it difficult to raise sexual issues with my doctors. However, once I had done it with one, it became much easier to talk about. For others I would suggest raising it with their most sympathetic doctor first. Once over that hurdle it won’t be so bad if you get a doctor who is uncomfortable discussing it – you’ll know it’s their problem, not yours.

My life is different now; I am different now, but still the same. It’s a part of my life I wouldn’t have missed. I’ve learned a lot, and grown a lot.

And I’m still here.

Love and cherish

Breast cancer has improved my sex life.

Breast cancer brought me and my husband face to face with my mortality. It also brought us closer together. We ceased taking each other for granted; we ceased assuming that the other one knew we loved them; and we ceased having any hang-ups about our imperfect bodies.

Post-treatment, and even during treatment, we have more time for each other. We are more open to the other’s needs and we are both far more free to express our own needs. The fear of losing each other through my death helps us cherish our time together. The result is our love life is the best it’s ever been.

This improvement in our sex lives is certainly unexpected and something I’ve not encountered in any of the cancer literature. I wonder if anyone else has had the same experience.
Accepting change

I have always considered myself as a very sexual person, so the diagnosis of breast cancer was doubly scary; would I die, or would I live with a deformity? The reality is much less traumatic. Since my husband and I were assured the partial mastectomy plus radiotherapy was just as effective (for my type of cancer) as a full mastectomy, I opted for the partial. It has been 12 months since my radiotherapy finished and my breast still doesn’t look ‘normal’. It probably never will. I still feel just as sexual as I ever did. My boob doesn’t look like its mate, but it doesn’t look too horrid, or maybe I’m just used to it!

I guess my main problem has been my husband. He’s been wonderfully supportive and all things marvellous but for some months afterwards he just felt ‘loving’ towards me; protective and caring, but not sexual. I found this very difficult; not because I felt like a freak or anything, but because I wasn’t having my emotional and sexual needs met by him. I just had to accept that this was the way he felt. I met my own sexual needs.

More than 10 years earlier, his first wife had died from a different type of cancer. Although awful for him, this actually made it easier for me, as I knew that his reaction was the same this time as it was last time. It wasn’t about me, or the way I looked.

As mentioned, it’s been 12 months since treatment ended and now I’d say our sexuality is back to normal. My husband doesn’t seem to differentiate (much) between one breast and the other (the left one is still a bit sore anyhow). It certainly doesn’t seem to put him off in any way. Likewise, I don’t try to hide it, nor do I dress any differently than I did before.

Cheryl

Taking time

When my husband and I celebrated our 10th wedding anniversary our two boys were too young for us to have a celebratory weekend away alone, so with our 15th anniversary approaching, I started planning months in advance.

After years of living in rural and remote Australia, we settled on three days of luxury in Brisbane to enjoy all the pleasures of the big city. Then, a month before our anniversary, I was diagnosed with breast cancer. We checked into our luxury cottage with me minus my left breast and the scar hidden beneath dressings, the wound drain having been removed the day before. Not exactly a sexy state to be in! And so very emotionally fragile too.

When I look back on it, I am so grateful that those days away – just us, no kids, in a setting conducive to intimacy – were already in place. In that setting we were having sex a week after my surgery and I am quite sure it would have taken a lot longer otherwise.

Post-surgery biopsy revealed invasive cancer too so three months of chemotherapy followed. Losing my hair had a bigger impact on my self-esteem and sense of my own attractiveness than losing my breast. Aside from feeling so sick I found it very hard to believe that my husband could possibly find me desirable. His patience and kindness and his acknowledgement that he too was mourning the loss of my breast, deepened our emotional intimacy.

I started going back to the gym weeks after surgery and have found rebuilding the strength and tone of my body and my fitness level – as well as of course my hair growing back – has been the most helpful thing in helping me to feel positive about my one-breast body. In the end I would say our sex life has not suffered because of my breast cancer experience, and may even have been enhanced because of our increased emotional closeness.

Emma

From the MJK

Photo from the My Journey Kit (MJK).
Take off Your Party Dress: When Life’s too Busy for Breast Cancer

By Dina Rabinovitch, Pocket Books, 2007 (paperback)
258 pages, RRP: $24.95

I must admit that this book grabbed my attention from the beginning. Dina Rabinovitch has what I call a ‘conversational style’ of writing, taking the reader into her home and life.

Underlying the story of her cancer experience are three main facets of her life – young wife and loving mother of a blended family of eight children, successful journalist with a regular column in The Guardian, and orthodox Ashkenazi Jewish woman – all of which play a large part in many of the decisions and choices she makes, and contribute greatly to the story she tells.

The book covers three years in the life of the author, from her initial diagnosis at around 40 years of age to a diagnosis of secondary breast cancer just over two years later. She writes honestly, with humour and courage and sometimes anger and frustration, of her experiences and the people who care for her during this time. Her decision to participate in very new drug trials sometimes leads to disappointment and unpleasant side effects, but although I feel her pain and sadness at the path her cancer seems to be taking, I find her courage in the face of adversity quite inspiring.

Fashion and appearance are also important to Dina and she has some great practical solutions to problems such as coping with limited movement and finding clothing which is comfortable as well as suitable for her busy lifestyle. Her determination not to lose her identity and her sense of humour allow her to retain some sense of control and bring a feeling of optimism to her story.

Above all, I think Dina is a great storyteller and for that reason, this book could appeal to a wide age range. It does confront some sensitive issues and may be difficult for newly diagnosed women, young women or some women with secondary breast cancer, although many will find it inspirational.

Robin Gregory,
NSW BCNA Review and Survey Group Member

Why I Wore Lipstick to My Mastectomy

by Geralyn Lucas, St Martin’s Griffin, 2005 (paperback)
224 pages, RRP: $21.95

My initial reaction on seeing the stunning photo on the front cover of this book was why would you use a model for the picture? However, it turns out to be the author herself. The picture alone gives you hope and makes you feel positive about what you are going to read – she looks stunning!

I read the book in two days and could not put it down. It is written in such an upbeat manner and even the heart-rending parts show the amazing inner strength of Geralyn. She is smart, bright, sassy, funny, cheeky and strong. It is a really uplifting read, as despite everything, Geralyn continued to work, travel, socialise and generally live her life to the fullest extent possible.

Some parts really touch the reader, especially a reader who may have experienced some of the difficulties she faced, that is medical staff not meeting her eye when diagnosed, people’s reactions on learning of her diagnosis, post-operative feelings, the realisation that she has lost not only a breast but also her nipple and how that affects her, trying to hang on to her career (which thankfully she does, in fact so well she even gets promoted during her treatment – fantastic hope for others), being advised not to start a family, etc.

The most poignant parts for me were the losing of her hair during chemo and the awful time she had trying to breastfeed. The breastfeeding experience fuelled by the ‘booby mafia’ is an experience that a lot of women can relate to.

I don’t feel that there were any negative aspects in the book; however, it was obvious Geralyn had endless resources to enable her to get numerous second opinions from the ‘Chanel, Gucci and Prada’ of private doctors in New York. She also had a huge support network to attend appointments with her as well as the money for the instant reconstruction. Not everyone has these opportunities and her experiences and lifestyle may be hard for some people to relate to depending on their situation.

Julia Wright
NSW BCNA Review and Survey Group member
The C-Word Group is a Sydney-based support group for lesbian women with cancer, and their partners.

It was established in 2005 by the NSW Cancer Council and ACON, Australia’s largest gay, lesbian, bisexual and transgender health organisation. These two organisations continue to support the group; facilitating group meetings and helping the group’s members find relevant information and supportive medical practitioners.

‘Our members all have different reasons for participating in the C-Word Group’, group facilitator Siri May explains. ‘Many have expressed their need to feel comfortable talking about their relationships in the context of their cancer experience in a group of like-minded women. It can be challenging to be honest about having a same-sex relationship in a group of primarily heterosexual women, and some women have experienced a feeling of marginalisation or even homophobia in mainstream support settings. This is not the experience of all our members, but to come out in a support group can cause added anxiety for women who are already contending with high levels of stress in relation to their cancer diagnosis.’

The group meets monthly and usually hears from a guest speaker.

‘Though being a lesbian is not a health problem, we sometimes find there can be discrimination which may lead to lower health outcomes for lesbian women,’ Siri says. ‘This can be related to lifestyle choices, lack of access to services with knowledge in lesbian health, fear of coming out to doctors, or even obtaining relevant health information. Discussions and speaker topics are mostly similar to those of non-lesbian groups. Being able to explore issues such as sexuality and intimacy following a cancer diagnosis is sensitive for any woman. In the C-Word Group our members can feel more comfortable speaking openly about their experiences both in the health system and in their personal lives as lesbians or in same sex couples.’

One member says, ‘I save up my thoughts and fears about my cancer to discuss with other C-Word Group members. During treatment they gave me the most relevant and up to date information so that I could make informed choices.’

Siri hopes that the success of the C-Word Group will provide encouragement for similar support groups to be established in other parts of Australia to address the needs of lesbians and same sex attracted women.

The facilitation of the C-Word Group is shared by Siri May from ACON and Kim Pearce from the NSW Cancer Council. Both are able to offer expertise in lesbian health. Siri can be contacted on (02) 9206 2007 or smay@acon.org.au. The ACON website, www.acon.org.au, has useful information, research and referrals for lesbians with cancer.

Kim can be contacted at the NSW Cancer Council on (02) 9334 1846 or kimp@nswcc.org.au.

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**Profiling our Member Groups**

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**Linking together**

We welcome the following new groups to make a total of 255 BCNA Member Groups around Australia:

- Breast Cancer Support Group, Hamilton, VIC
- Breast Friends Cancer Support Group, Hills Area, SA
- Support Network for Women with Breast/ Gynaecological Cancer, North West (Burnie), TAS
- Support Network for Women with Breast/ Gynaecological Cancer, North (Devonport), TAS
- Circular Head Bosom Buddies Tasmania, Smithton, TAS
- Dragons Abreast, Ballarat, VIC
- Wynyard Breast Awareness Group, TAS
- Southlakes Cancer Support Group, Morris, NSW

You can visit our website to find a Member Group, including support groups, in your state or territory at www.bcna.org.au > About BCNA > Member groups.
We appreciate the financial support given to us by individuals, clubs, organisations and companies around Australia. We would especially like to acknowledge the recent help of the following outstanding supporters:

- Anita McAllister, QLD
- Donna Millwood, TAS
- Carey Baptist Grammar School, VIC
- G-Force Recruitment, VIC
- Griffith Breast Cancer Support Group, NSW
- Home Support Services, SA
- Ina Fulbohm, QLD
- Jasol Australia – a division of George Western Foods Ltd, WA
- Jillian Lawrow, VIC
- Jolanta Lesniak, WA
- Julie Austin, VIC
- Karron Dean, NSW
- Kingswood Golf Club, VIC
- Lana Dennis, VIC
- Lyndsey Cattermole, VIC
- Michael Sowards & Adam Begg, VIC
- Mt Gambier Breast Cancer Luncheon Group, SA
- Pascoe Vale Girls College, VIC
- Phil Moreau, SA
- Warilla Grove, NSW
- Warrawong, NSW
- Wollongong, NSW
- The Michael and Andrew Buxton Foundation, VIC
- Thirteenth Beach Golf Links, VIC
- Winefriends, VIC

Memorials

We pay tribute to the lives of:

- Anne Cabassi
- Diane Cole
- Ginette Petruolo
- Jan Munro
- Jan Smith
- Jeanette Higgins
- Karen Bourke
- Laura Stephenson
- Lorraine Morris
- Maree Lawler
- Mary Barnett
- Rosemary Marven
- Sue Lockwood

We are grateful for the donations we received in their memory.

Celebrations

Thank you to those who asked their friends to donate to BCNA to celebrate their special day.

Happy Birthday to

- Dorothy Fletcher
- Jackie Leach
- Margaret White
- Sandra Annison

Congratulations to Kim and Thomas Van De Hoef, and Eve Bottrill and Jason Kitchingman on their recent marriages.

14-year-old Sean Harris is a young BCNA champion. To show support for his mum, Tina, a breast cancer survivor, Sean competed in the 9km event at the Blackmores Sydney Running Festival and donated his sponsorship proceeds to BCNA. He also coordinated a chocolate drive at his school. In total, Sean has raised more than $1,500 for BCNA. Great effort!

BCNA’s Catherine Nolan with Irish singer and breast cancer campaigner Ronan Keating and the Pink Lady. Ronan met with BCNA representatives during his recent Australian tour to discuss the work of the Marie Keating Foundation in Ireland and the UK, a charity he set up following his mother’s death from breast cancer in 1998. Clearly passionate about the cause, Ronan was keen to hear about BCNA’s work.
Pink Bun campaign is just around the corner

What is Pink Bun all about?

• The annual Pink Bun campaign will run for three weeks from Thursday 22 April to Wednesday 12 May in the lead-up to Mothers’ Day
• All 630 Bakers Delight bakeries around Australia will be decorated in pink and will sell pink buns, tarts and paper pink ladies
• They will raise funds for BCNA and raise awareness of the support available to those affected by breast cancer
• BCNA members and Member Groups will work with their local bakeries to promote the services of both BCNA and its support groups.

‘It was fabulous. I loved meeting so many people in the community. It is amazing how many of them have been touched by breast cancer. We shared stories, had lots of laughs and some tears. Can’t wait for next year.’ – Sam, BCNA Member, SA

How do I get involved?

• Go to our website www.bcna.org.au to keep up to date with the Pink Bun Campaign
• Visit your local bakery and purchase a pink treat or two
• During the first week of the campaign buy a paper pink lady to help your bakery win a prize for the most paper pink ladies sold

• Write a message of support on a paper pink lady
• Spread the word about the Pink Bun campaign
• Vote online for your favourite best-dressed bakery in the Pink Bun awards at www.bcna.org.au

If you are someone keen to do that extra bit for the cause, we are looking for great BCNA women to help us at local bakeries. If you think you would like to help out, contact Marita on pinkbun@bcna.org.au

Bakers Delight staff love to meet women who have benefitted from Pink Bun fundraising which has helped BCNA to develop free resources, such as the My Journey Kit and The Beacon. Many customers also appreciate the opportunity to speak to BCNA members about their breast cancer experiences.

This year marks the milestone of a wonderful 10-year partnership between Bakers Delight and BCNA. During this time more than $3.7 million has been raised by Bakers Delight to support the work of BCNA.

Bakers Delight staff are proud of their commitment to us, and we are overwhelmed by their enthusiasm in making a real difference locally and nationally for those personally affected by breast cancer.

Facts and stats

Did you know the risk of getting breast cancer increases with age, and that the average age of first diagnosis is 60?

If you are interested in learning about breast cancer in Australia, you may like to read BCNA’s Statistics in Australian Breast Cancer. It is designed to provide the most up-to-date information in an easy to read format.

The document highlights the significant impact breast cancer has on the Australian community, and why we must continue to raise awareness and provide support to women and their families.

It is estimated that approximately 14,000 women will be diagnosed with breast cancer in 2010. Importantly, more women are living significantly longer after their diagnosis and treatment than ever before.

Statistics in Australian Breast Cancer can be downloaded from our website www.bcna.org.au or phone us on 1800 500 258 (freecall) and we will send you a copy.
Upcoming events

March 29 (Monday): We are pleased to announce that BCNA will host a forum ‘Living well beyond breast cancer’ in Tamworth. Please check our website, www.bcna.org.au, for more details and to register.

April – May: Thursdays, between 1.30pm and 3.30pm, the Royal Women’s Hospital in Melbourne is running a free menopause program specifically for women who have experienced early or surgical menopause as a result of cancer. The seven sessions will include physical symptoms, sleep, diet, exercise, moods and sexuality. For information or bookings contact the Women’s Hospital on (03) 8345 3045 or email whic@thewomens.org.au

April 22 (Thursday): BreaCan will present a free workshop ‘Breast Reconstruction – What You need to Know’, 12pm to 1.30pm, Queen Victoria Women’s Centre, 2B Lonsdale St, Melbourne. For information or bookings, phone 1300 781 501.

Your stories

Join us on the MCG

Friday 7 May 2010
Field of Women LIVE

Visit www.fieldofwomenlive.org.au to register and for all the latest news about the night.

May 8-9: Pink Footy/Netball Day 2010. Local football and netball clubs will turn pink on the Mothers’ Day Weekend to support BCNA. Clubs participating will be playing with a specially designed pink football or netball. For more information and to find out if there is a game in your local area, visit http://www.pinkfootynetballday.org.au

May 16 (Sunday): The Sydney Morning Herald Half Marathon presented by Colonial First State. BCNA is once again the lead charity for this event. If you would like to register to participate in the 21km race and to fundraise for BCNA, visit http://halfmarathon.smh.com.au. Don’t forget to wear a touch of pink on the day to show your support for BCNA.

Your stories

Communities

We are seeking stories about communities for the Spring 2010 issue of The Beacon.

What does community mean to you? Has your experience with breast cancer changed your idea of what a community is? Have you found a new community or network? Do you meet face-to-face or have you ventured on to the internet? Tell us about your experience, thoughts or reflections.

Please email articles of 200-300 words (about half a page) to beacon@bcna.org.au by the end of June 2010.

Please also include a high-resolution digital photo, or post your photo to us, and we will return it to you.

May 8-9: Pink Footy/Netball Day 2010. Local football and netball clubs will turn pink on the Mothers’ Day Weekend to support BCNA. Clubs participating will be playing with a specially designed pink football or netball. For more information and to find out if there is a game in your local area, visit http://www.pinkfootynetballday.org.au

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